



RESEARCH ARTICLE

PERCEIVED NEED-FULFILLMENT AMONG FAMILY CAREGIVERS OF CANCER PATIENTS

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ARTICLE INFO

Article History:

Received 29<sup>th</sup> December, 2017

Received in revised form

05<sup>th</sup> January, 2018

Accepted 17<sup>th</sup> February, 2018

Published online 23<sup>rd</sup> May, 2018

Key words:

Need-Fulfillment,  
Family Caregiver, Cancer Patients.

ABSTRACT

**Introduction:** Family caregivers of cancer patients provide extraordinary uncompensated care that is physically, emotionally, socially, and financially demanding and results in the neglect of their own needs. Satisfaction of caregiving need of family caregiver is important for quality care the patient. In this direction present study was aimed at identifying the level of satisfaction with perceived need-fulfillment related to cancer caregiving among family caregivers of cancer patients.

**Methods:** Descriptive cross-sectional survey was conducted to assess the level of need-fulfillment among 225 conveniently selected family caregivers of cancer patient receiving chemotherapy and radiation therapy in a tertiary care hospital of Punjab by using socio demographic data sheet and Family inventory of Needs (FIN) scale. Data were analyzed using descriptive statistics, t-test, ANOVA and Pearson's correlation.

**Results:** The family caregivers were predominantly male (61.8%), married (80.9%) and belonged to Sikh religion (75.6%). Two third (64%) family caregivers had their perceived important needs only partially met. Mean (SD) of need-fulfillment was 39.22 (9.2) and it had significant association with gender of family caregivers ( $p=0.028$ ), distance of subject's residence from hospital ( $p=0.032$ ) and provision of unpaid help in caregiving activities ( $p=0.019^*$ ).

**Conclusion:** Majority of family caregivers had their important needs only partially met. Health care system needs to focus on the family caregivers and their perceived needs. Study recommends that oncological nurses should regularly assess the need-fulfillment of caregivers of cancer patient so that appropriate interventional strategies can be planned.

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Citation: Sharma Preksha, Mahal Rajinder Kaur and Maheshwari, S.K. 2018. "Perceived Need-fulfillment among Family Caregivers of Cancer Patients.", *International Journal of Current Research*, 10, (05), 69192-69197.

INTRODUCTION

The concern related to cancer extends to not only have a significant impact on the affected patients, but also on their families. Family caregivers provide extraordinary uncompensated care that is physically, emotionally, socially, and financially demanding and results in the neglect of their own needs (Schubart, 2007). Despite caregiving have a significant impact on caregivers' well-being, their needs are frequently considered secondary to those of the patient or are overlooked (Payne, 1999). Some research studies has suggested that family caregivers of people with cancer may have more unmet care needs than patients (Silveira, 1997). Family caregivers' needs in relation to caregiving of cancer patient, information, support and communication are all important (Janda et al., 2008; Kristjanson, 2002; Fridriksdottir et al., 2006) but most of these needs are not adequately met

by health professionals (Janda et al., 2008; Kristjanson et al., 2002; Fridriksdottir et al., 2006; Kim et al., 2010). Unmet needs have been found to be associated with impaired work performance (Park et al., 2010), anxiety (Molassiotis, 2010), more caregiver burden (Sharpe et al., 2005) and less caregiver satisfaction (Hwang et al., 2003). Family caregivers are a vulnerable and at-risk population that remains neglected by the health care system ([www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp). Accessed jan 26, 2018.) and without any type of intervention, the physical and emotional health of the caregiver will continue to suffer. This elevated risk poses a problem not only for the caregiver's well-being, but also may impact their ability to provide complex care to another when their own physical and mental health is compromised (Park et al., 2010; Molassiotis, 2010). Thus, in order to ensure optimal caregiving, effort to understand and ameliorate the negative consequences of caregiving appears to be a reasonable area of consideration. Most studies assessing unmet needs have been conducted in later stages of illness, though there are the evidences that, unmet caregiver needs are more common in conventional hospital units than in specialized palliative care

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settings (Fridriksdottir, 2006). Keeping in mind all these issues and paucity of literature addressing needs of the family caregivers related to cancer caregiving in India current study was undertaken that aimed to understand the level of satisfaction with perceived need-fulfillment related to cancer caregiving among family caregivers of cancer patients.

## MATERIALS AND METHODS

A descriptive, cross sectional survey was done to assess the perceived needs fulfillment of family caregivers of cancer patients and its relationship with selected socio- demographic variables of family caregivers of cancer patients undergoing chemotherapy and radiation therapy in selected cancer OPD of tertiary care level hospital of Punjab. Family caregivers who accompanied cancer patient during first cycle of chemotherapy/ first day radiation therapy, who were living with cancer patient, who were able to understand Punjabi/ English, willing to participate and nominated by cancer patient to provides significant care at home were included in the study. Family caregivers were not eligible for the participation if the family caregiver was unable to cooperate due to physical, psychological or emotional reasons. Two hundred twenty five family caregivers of cancer patients were conveniently recruited for study. The tools used for the study were Socio demographic Data Sheet and Modified Need-fulfillment Sub Scale of Family inventory of Needs (FIN) which are as follows:

**Tool No. 1: Socio-demographic data sheet:** Socio-demographic data sheet used for measuring of socio-demographic and caregiving information of the family caregiver. Administration time is approximately 5-6 minutes. Items included were age, gender, religion, marital status, education, occupation, family income, type of family, residence, distance from treatment centre, presence of any comorbid chronic illness in family caregivers, relationship with patient, Duration care giving in months, Amount CG (hrs/day), provision of unpaid help in caregiving, provision of paid help in caregiving and patient's diagnosis. Appropriate content validity of the tool was established by experts. The reliability was established through test retest method ( $r=1$ ).

**Tool No. 2: Modified Need-fulfillment Sub Scale of Family inventory of Needs (FIN)<sup>235</sup>:** Need-fulfillment Sub Scale of Family inventory of Needs is a twenty items standardized, reliable tool to measure 20 needs identified by some family members of cancer patients. FIN- fulfillment of need subscale is slightly modified for current study with permission from original developer. Scale is modified to make it a rating scale. In original scale, respondent is asked to score a "met response" as 1 and "not met" as 0 for each item of scale. Scoring is slightly modified, and respondent is asked to rate each item from 0-4.

A score of zero means need is not important. Scores from 1-4 means that the need is important and also reflects the level to which family caregiver perceives his/her care needs have been met (0 = need is not important, 1 = need is important but not met at all, 2 = need is important and partly met, 3 = need is important and well met, 4 = need is important and completely met). Thus scores ranges from 0-80. Higher score mean high satisfaction with fulfillment of needs that are perceived important by the participants. Administration time is approximately 5-7 minutes.

Reliability of the tool for present study was  $r= 0.89$  and  $\alpha= 0.82$ . The tools were translated into local Punjabi language. Try out of the tool and pilot study was conducted and the study was found to be feasible.

**Ethical considerations:** Prior to administration to tools, an informed written consent form was signed by the each subject before data collection. All the subjects were ensured that confidentiality and anonymity will be maintained throughout the study. Permission was obtained from Institutional Ethical Committee to carry out the study. Written permission was also obtained from Medical Superintendent of selected hospital.

## STATISTICAL METHODS

The data was analyzed by SPSS- 21. The  $p<0.05$  level was established as a criterion of statistical significance for all the statistical procedures performed. Appropriate descriptive and inferential statistics were employed to analyze data as per objectives of the study. Frequency and %age distribution of sample characteristics was computed. Frequency, percentage and Mean (SD) of Need-fulfillment of family caregivers were calculated. Association between need-fulfillment and selected socio-demographic variables was determined by ANOVA or t-test.

## RESULTS

**Socio-demographic and clinical characteristics:** As shown in Table 1 and Table 2, the mean age of the family caregivers (N=225) was 40.98 (SD=12.2) years. The family caregivers were predominantly male (61.8%), married (80.9%) and belonged to Sikh religion (75.6%).

**Table 1. Distribution of subjects as per Socio-demographic Characteristics (N=225)**

Socio-demographic characteristics of caregivers		f (%)
Age	Mean (SD)	40.98 (12.2)
Gender	Male	139 (61.8)
	Female	86 (38.2)
Religion	Sikh	170(75.6)
	Hindu	54 (24)
	Christian	1 (0.4)
Marital status	Married	182 (80.9)
	Unmarried	37 (16.4)
	Widow/widower	6 (2.7)
Education	Upto 5 <sup>th</sup>	27 (12)
	Upto 10 <sup>th</sup>	105 (46.7)
	Upto 12 <sup>th</sup>	69 (30.7)
	Graduation and above	24 (10.4)
Occupation	Unemployed	7 (3.1)
	Govt service/ Retired	18 (8)
	Labor	7 (3.1)
	Self employed	73 (32.4)
	Homemaker	43 (19.1)
Family Income/ year	Student	24 (10.7)
	Agriculture	53 (23.6)
	<1 Lakh	56 (24.9)
	1-3 Lakh	96 (42.7)
	> 3-5 Lakh	54 (24)
Type of family	>5 Lakh	19 (8.4)
	Nuclear	71 (31.6)
	Joint	119 (52.9)
Residence	Extended	35 (15.6)
	Rural	155 (68.9)
	Urban	70 (31.1)

All the participants were literate with maximum (46.7%) educated upto tenth standard. Maximum participants were self employed (32.4%) with yearly family income of maximum subjects (42.7%) was between 1-3 lakhs/year.

**Table 2. Distribution of subjects as per their care giving related characteristics (N=225)**

Care giving related characteristics of caregivers		f (%)
Distance from hospital	Local	44 (19.6)
	Other district	181 (80.4)
Chronic disease	No	207 (92)
	Yes	18 (8)
Relationship with patient	Child	75 (33.3)
	Spouse	95 (42.2)
	Daughter in law	26 (11.6)
	Parents	6 (2.7)
	Siblings	15 (6.7)
	Others	8 (3.6)
Duration care giving in months	Mean (SD)	4.96 (3.2)
Amount CG (hrs/day)	Mean (SD)	5.84 (1.78)
Unpaid help	No	11 (4.9)
	Minimum help	119 (52.9)
	Sufficient help	95 (42.2)
Paid help	No	122 (54.2)
	Yes	103 (45.8)
Diagnosis of patient	Breast	56 (24.9)
	Cervix	40 (17.8)
	Head and neck	58 (25.8)
	GI tract	27 (12)
	Reproductive	22 (9.8)
	Others	22 (9.8)

**Table 3. Mean (SD) score of subjects as per their perceived need-fulfillment (N=225)**

	Range	Mean (SD)
Need-fulfillment	24-67	39.22 (9.2)

**Table 4: Relationship of selected socio-demographic characteristics with need-fulfillment score (N=225)**

Socio-demographic characteristics		f (%)	Mean (SD)	t/F	Df	p value
Gender	Male	139 (61.8)	40.29 (9.4)	2.205	223	0.028*
	Female	86 (38.2)	37.50 (8.7)			
Religion	Sikh	170(75.6)	39.05 (9.2)	1.322.	2	0.269
	Hindu	54 (24)	39.50 (9.3)			
	Christian	1 (0.4)	54.00 (-)			
Marital status	Married	182 (80.9)	39.30 (9.5)	0.047	2	0.954
	Unmarried	37 (16.4)	38.97 (8.3)			
	Widow/widower	6 (2.7)	38.33 (9.6)			
Education	Upto 5 <sup>th</sup>	27 (12)	37.37 (10.2)	1.167	3	0.323
	Upto 10 <sup>th</sup>	105 (46.7)	38.70 (9.1)			
	Upto 12 <sup>th</sup>	69 (30.7)	39.86(9.4)			
Occupation	≥Graduation	24 (10.4)	41.75 (8.2)	0.779	6	0.587
	Unemployed	7 (3.1)	42.57 (8.3)			
	Govt service/ Retired	18 (8)	41.72 (9.5)			
	Labor	7 (3.1)	36.43 (7.4)			
	Self employed	73 (32.4)	39.27 (10.1)			
	Homemaker	43 (19.1)	37.40 (9.1)			
Family Income/ year	Student	24 (10.7)	39.08 (8.6)	1.612	3	0.188
	Agriculture	53 (23.6)	39.77 (8.7)			
	<1 Lakh	56 (24.9)	37.73 (9.1)			
	1-3 Lakh	96 (42.7)	39.04 (9.1)			
Type of family	> 3-5 Lakh	54 (24)	39.76 (9.5)	-1.170	223	0.243
	>5 Lakh	19 (8.4)	43.00 (9.5)			
	Nuclear	71 (31.6)	38.04 (8.4)			
	Joint	119 (52.9)	39.66 (9.9)			
Residence	Extended	35 (15.6)	40.14 (8.7)	-1.170	223	0.243
	Rural	155 (68.9)	38.74 (9.0)			
	Urban	70 (31.1)	40.30 (9.8)			
Distance from hospital	Local	44 (19.6)	41.91 (11.5)	2.156	223	0.032*
	Other district	181 (80.4)	38.57 (8.5)			

\*\* Significant at the 0.01 level

Majority of the subjects belonged to joint family (52.9) and were residing in rural area (68.9%). Maximum (42.2%) caregivers were spouse followed by children (33.3%). Family caregivers were providing care from a mean duration of 4.96 (3.2) months with an amount of caregiving being mean 5.84 (1.78) hrs/day. Maximum (52.9%) participants reported to get minimum unpaid help followed by (42.2%) getting sufficient unpaid help in caregiving.

Paid help in caregiving had to be taken by 45.8% participants. Majority (80.4%) participants belonged to other districts and (19.6%) participants were local. Chronic disease was present in eight percent caregivers. Among all cancer cases, head and neck cancer was at top (25.8%). Table 3 states that the mean (SD) of need-fulfillment was 39.22 (9.2) and it range from 24 to 67. As shown in figure 1, 64% of family caregiver had their perceived important needs only partially met whereas only

**Table 5. Relationship of selected caregiving characteristics of caregiver with need-fulfillment score (N=225)**

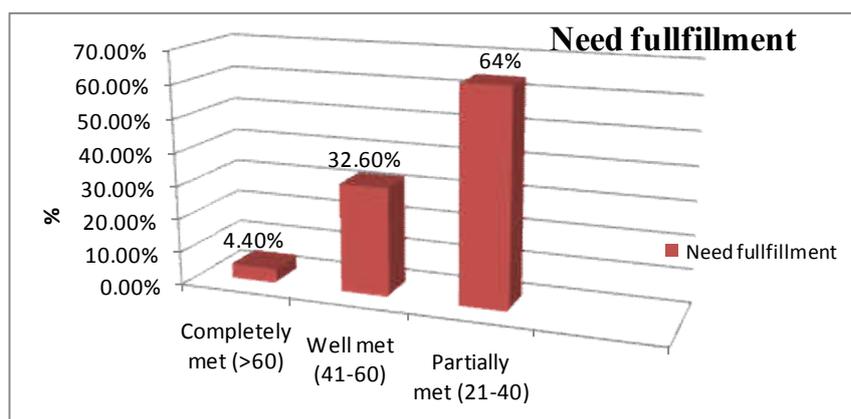
Selected care giving characteristics of subjects and clinical characteristics of patients		f (%)	Mean (SD)	t/F	Df	p value
Chronic disease	No	207 (92)	39.16 (9.4)	-0.343	223	0.732
	Yes	18 (8)	39.94 (6.9)			
Relationship with patient	Child	75 (33.3)	39.13 (7.9)	0.726	5	0.605
	Daughter in law	26 (11.6)	37.58 (8.3)			
	Others	8 (3.6)	38.38 (7.8)			
	Parents	6 (2.7)	40.83 (12.5)			
	Siblings	15 (6.7)	43.07 (9.8)			
	Spouse	95 (42.2)	39.11 (10.3)			
Unpaid help	No	11 (4.9)	38.82 (12.0)	4.036	2	0.019*
	Minimum help	119 (52.9)	37.61 (8.1)			
	Sufficient help	95 (42.2)	41.18 (9.9)			
Paid help	No	122 (54.2)	39.39 (10.2)	0.300	223	0.764
	Yes	103 (45.8)	39.02 (8.1)			
Diagnosis of patient	Breast	57 (25.3)	38.46 (8.3)	1.270	5	0.278
	Cervix	39 (17.3)	41.15 (9.2)			
	GI tract	25 (11.1)	41.44 (11.2)			
	H & N	60 (26.2)	37.37 (8.5)			
	Others	22 (9.8)	40.50 (10.2)			
	Reproductive	22 (9.8)	39.05 (10.0)			

\*\* significant at the 0.01 level

**Table 6: Relationship of family caregiver's age , duration of caregiving and amount of caregiving with Need fulfillment (N=225)**

	Age of caregiver	Duration of caregiving	Amount of caregiving
Need-fulfillment	0.050	0.568**	-0.082

\*\* Correlation is significant at the 0.01 level (2-tailed).

**Fig. 1. Frequency percentage distribution of subjects as per their need-fulfillment score**

4.4% of the subjects perceived that their important need regarding caregiving were met completely. Thus, it can be said that important needs of maximum of the family caregivers were only partially met. As shown in Table 4, need-fulfillment had a statistically significant association with gender of family caregivers ( $p=0.028$ ) and distance of subject's residence from hospital ( $p=0.032$ ). Males were having significantly more need-fulfillment in comparison to females. Those family caregivers who were coming from more distance for treatment of their relative, had significantly less need-fulfillment in comparison to subjects who were local and had less distance of their residence from hospital. As shown in Table 5, need-fulfillment had a statistically significant association with provision of unpaid help in caregiving activities ( $p=0.019^*$ ). Family caregivers who were receiving sufficient unpaid help in caregiving activities perceived significantly highest need-fulfillment related to their caregiving role. As Table 6 shows, duration of caregiving had a significant large positive correlation with need-fulfillment ( $r=0.568^{**}$ ,  $p=0.01$ ). Hence, it can be concluded that family caregivers who were providing care to their patient for long duration perceived high need-fulfillment.

## DISCUSSION

The present study is an attempt to recognize the perception of need-fulfillment among family caregivers of cancer patients. In present study, the mean need-fulfillment score for caregivers was 39.22 (9.2) and it was concluded that family caregivers had low level of satisfaction with fulfillment of need related to caregiving role. Majority (64%) of family caregivers in the study reported that they had their important needs as only partially met. Consistent findings are reported by other studies where family caregivers reported to have many of their needs unmet. Houts *et al.* (1996) in a survey of 397 caregivers found that 51% of the sample had at least one unmet need. A cross-sectional, descriptive study of 223 FCGs of cancer patients conducted by Nanna *et al.* (2011) found that twelve important needs were unmet in 40–56% of the sample. Clavarino *et al.* (2002) also reported that 19 FCGs of cancer patients receiving RT had moderate to high levels of unmet psychological need. Another study by Grobe (1981) *et al* with families of 87 advanced stages of cancer perceived that little, if any, education was provided to them. Hinds (1985) reported that most of family caregivers needed numerous informational

and had skill deficits. Oberst *et al.* (1989) reported that more than one third of caregivers had a lack of assistance from health professionals in providing care. In another study (Perry, 1989) 85% of a sample of cancer caregivers failed to utilize available resources to assist them in caregiving activities. Persson *et al.* (1998) also identified that caregivers who wanted to help in any way that they could, but felt that the healthcare staff did not use them as a resource. These caregivers described their healthcare workers as absent, misunderstanding their situation, or not asking about their feelings. These studies uncovered a contradiction that although caregivers want to assist their family member, health care providers do not always recognize them as a resource. In addition several qualitative nursing research studies also indicated that information and supportive needs were a primary concern for family caregivers and these needs were either not fully met or were only partially met (Hudson, 2002; Turner *et al.*, 2013). This low level of satisfaction regarding fulfillment of perceived needs among family caregivers in current study is the reflection of health care system that focuses only on patients whereas needs of family caregivers are considered secondary or totally overlooked. In present study, need-fulfillment was also found significantly associated with gender of caregiver, distance of subject's residence from hospital, and unpaid help. Males were having significantly more need-fulfillment in comparison to females. In study conducted by Perz *et al.* (2011) women reported significantly more unmet needs than men. Those family caregivers who were coming from more distance for treatment of their relative, had significantly less need-fulfillment in comparison to subjects who were local and had less distance of their residence from hospital. This may be understood in light of consistent previous finding reporting that errands or transportation can increase caregiver distress (Gonzalez-Salvador, 1999; Weitzner *et al.*, 1999).

This distress, frustration and other problems associated with increased transportation requirement among family caregivers coming from more distance for treatment of their relative, might have produced a feeling of lack of satisfaction with need-fulfillment. Family caregivers who were receiving sufficient unpaid help in caregiving activities perceived significantly highest need-fulfillment related to their caregiving role followed by those not receiving any unpaid help and those receiving only minimum unpaid help. It may be understood as in Indian culture, unpaid help in most of cases is received from social support system. So this association of need-fulfillment with unpaid help may actually be a reflection of correlation between need-fulfillment and social support. Social support can be of particular significance for persons in caregiving situation either by providing a sense for the fulfillment of emotional needs (e.g., affection, esteem, or companionship) and/or instrumental needs (e.g., advice, practical help, or financial aid, "problem-oriented" and "daily" support (Suurmeijer *et al.*, 1995; Chan, 2011). Family caregivers who were providing care to their patient for long duration perceived high need-fulfillment. The possible explanation may be that with the increasing duration of caregiving family caregivers might have learned how to mobilize the resources in order to get help in their caregiving related responsibilities. They might also have been learned some caregiving skills by experience or may have gathered more information regarding caregiving that would have proved beneficial in their caregiving related needs. All these possible events that have been taken place with time could have

possibly increased their sense of perceived need-fulfillment related to caregiving.

## Conclusion

Study concluded that majority of family caregivers of cancer patient had their important needs as only partially met. Female gender, more distance of residence from hospital and lack of unpaid help in caregiving activities were found to be significantly associated with less satisfaction for need-fulfillment, whereas family caregivers who were providing care to their patient for long duration perceived high need-fulfillment. Health care system needs to focus on the family caregivers and their perceived needs. Extension of tertiary care centers providing cancer treatment along with other tested measures are needed to address the problems faced by cancer patients and their family caregivers coming from far places for treatment. Community based support intervention specially for vulnerable groups such as for female caregivers and those having less support system are needed.

## Implications and Recommendations

The findings of this study bring in the notice that most of important needs of many family caregivers of cancer patients are either not met at all or only partially met. In this scenario responsibility lies on nurses and other health-care professionals to assess the need of this vulnerable group going through such a stressful period of life. Studies are needed to test the interventions targeted to enhance the sense of having their important needs (related to caregiving) fulfilled and thus enhancing the sense of being valued by our health care system. Consumer satisfaction is having increasing importance in modern health science management. Furthermore multi-site studies with a larger sample and will enforce evidence based practice.

## Limitations

Self report method was used to collect data in current study. This study adopted a cross sectional design and is limited to the family caregivers of cancer patients from a single setting.

**Acknowledgement:** Nil

**Financial and Material Support:** Self

**Conflicts of Interest:** None

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